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**LEVELS OF HOPE IN PARENTS
OF
CHRONICALLY ILL CHILDREN**

**A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of science**

By

**Perry A. Carlson
B. S. N., Florida State University, 1993**

**2002
Wright State University**

WRIGHT STATE UNIVERSITY
SCHOOL OF GRADUATE STUDIES

May 28, 2002

I HEREBY RECOMMEND THAT THE THESIS PREPARED UNDER MY
SUPERVISION BY Perry Albert Carlson ENTITLED Levels of Hope in Parents of Chronically
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THE DEGREE OF Master of Science.

Janet S. Fulton
Janet S. Fulton, Ph.D., R.N.
Thesis Director

Patricia A. Martin
Patricia A. Martin, Ph.D., R.N.
Dean, College of Nursing and Health

Committee on
Final Examination

Janet S. Fulton
Janet S. Fulton, Ph.D., R.N.

Tracey L. Steele
Tracey L. Steele, Ph.D.

Patricia Vermeersch
Patricia E. H. Vermeersch, Ph.D., R.N.

Joseph F. Thomas, Jr., Ph.D
Dean, School of Graduate studies

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DEDICATION

First and foremost I want to thank my Lord and savior Jesus Christ for my eternal salvation and meeting all my needs. To my wife Andrea and my children Alisia and Danae, thank you for supporting me through my Master's degree, broken foot and all. I would also like to thank Dr. Fulton for all her patience and guidance in this arduous endeavor. And finally, thanks to Dr. Steele and Dr. Vermeersch for agreeing to be on my thesis committee and for all their constructive input.

ABSTRACT

Carlson, Perry A. M.S., Wright State University-Miami Valley College of Nursing and Health Wright State University, 2002. Levels of Hope in Parents of Chronically Ill Children.

The concept of hope is a common facet of human existence that most, if not all, share in the journey through life. Hope is a process that relates to areas of rational thought, relationships, experiences, and the spiritual or transcendent realm. In the scientific literature, hope has been positively correlated with quality of life and health outcomes. Functionally, hope has been viewed as a prerequisite to coping, as a coping strategy, and as an outcome in and of itself. As such, it is an important consideration in dealing with patients and their families.

In the United States approximately 10.3 million children are faced with some type of chronic illness. Parents of these children face added challenges that bring additional burdens of care and stress. Hope has been shown to be involved in coping with stress, but there is very little in the current literature about levels of hope in caregivers and even less dealing with parental hope.

This study measures the levels of hope in parents of chronically ill children and examines the possible correlation between the level of disability the parents perceive in relation to their chronically ill child and the parents' level of hope.

Instruments used in this study include the Herth Hope Index (HHI) and the Amount of Assistance Questionnaire (AAQ) parts I and III. The HHI, developed by Kaye Herth, quantitatively measures hope. Parental perception regarding their chronically ill child's level of disability was measured by the AAQ, developed by Michael Msall to identify the amount of assistance required by a chronically ill child.

The population for this study were parents of children diagnosed with asthma, cerebral palsy, diabetes, or epilepsy, all of whom were seen in the participating hospital within the last 6 months. Surveys were then mailed to the home addresses of the identified children along with a cover letter and return, postage paid envelopes. Parents of the chronically ill children, if they choose to participate, filled out the questionnaires and mailed them using the return envelopes. The surveys were collected by the researcher and statistical analysis of the data were performed by the Wright State University Statistical Consulting Center.

The response rate for the surveys was 19% resulting in a total of 58 returned surveys. Of these, 2 were not included in the data analysis due to missing data, and 2 more rejected because the information was an exact duplicate of the paired survey. A total of 54 surveys were used for data analysis.

As anticipated, no correlation was found between the amount of perceived disability, as measured by the AAQ, and parental levels of hope, as measured by the HHI. Parental levels of hope in this study were found to be

slightly higher than those of previous studies using the HHI in other populations.

Results of this study indicates that the child's level of disability did not, on its own, significantly affect the levels of hope in the parents. Therefore, should the clinician encounter a parent with low levels of hope, with a severely disabled child, it should not be assumed that the main cause is that their child is seriously handicapped. More assessment to ascertain the true cause of their low hope levels would be warranted.

Also, more needs to be know in regards as to what factors have major impacts on parental hope, especially in the arena of chronic illness in children. Other variables that may impact hope, such as length of illness, marital discord, and the visibility of the child's condition, need to be explored. Additional research in this domain is needed to expand current knowledge, validate or disprove conclusions of earlier studies, and piece together the complex interrelation of the issues impacting families with chronically ill children.

I. INTRODUCTION

The concept of hope is a common facet of human existence that most, if not all, share in the journey through life. Hope is a process that relates to areas of rational thought, relationships, experiences, and the spiritual or transcendent realm. Positive correlation of this concept to health outcomes and quality of life has been solidly established in the scientific literature. Functionally, hope has been viewed as a prerequisite to coping, as a coping strategy, and as an outcome in and of itself. As such, it is an important consideration in dealing with patients and their families.

Approximately 14.8% of children in the United States, 10.3 million, face life with some type of chronic illness. While 20 years ago many children with severe chronic illnesses died at a young age, today more than 85% survive to adulthood (Blum et al., 1993). What this means to clinicians is that more children are now being managed for chronic illnesses than ever before. A team approach, which includes the parents, is needed in treating chronically ill children because the parents have unique knowledge concerning their child and are ultimately responsible for the care the child receives (Jackson & Vessey, 1996).

Parents caring for these children face added responsibilities that can cause stress and tax family resources. Practical needs of the chronically ill child, such as medication administration, adherence to a special diet, or scheduling of medical appointments, are only the beginning of the added stressors parents of a

chronically ill child are required to deal with (Wallace, Biehl, MacQueen, & Blackman, 1997). Excessive time commitment, increased financial burdens, social isolation, role overload, and physical exhaustion are other common themes of stress expressed by parents caring for a child with a chronic illness (Eiser, 1993). Parents are often called upon to make complex decisions related to the child's condition, severity of symptoms, treatment options, and whether the treatments are effective (Eiser, 1993; Wallace et al., 1997).

Anxiety stemming from concern over if and when a child will have an acute attack, as in the case of asthma, makes it difficult for parents and other family members to relax. In addition, care-giving demands can create tension between the parents and limit the amount of time available for other children and family recreation. Siblings may feel left out because of all the attention the chronically ill child receives (Eiser, 1993).

A child's chronic illness also brings an additional financial burden to the family. Costs directly associated with medications, special equipment, and treatments are often defrayed by insurance, but are seldom completely covered. Modifications to the home and/or automobile, special diets, frequent travel to clinics or hospitals, and childcare for the affected child or siblings typically add to expenses. Income may be lost due to the need for one parent to be available at home full time (Eiser, 1993).

Because the care of these children falls predominantly on the parents, assisting them in successfully coping with stressors is of utmost importance. Hope has been described in the literature as a buffer for stress and required for

effective coping (Herth, 1993). Parental hope has also been shown to have a significant impact on a child's health outcome. A study of burned children by Seligman, MacMillan, & Carol (1971), reported a positive correlation between survival rates in severely burned children and the levels of hope in their parents. Quality of life for children with spina bifida was noted to be more significantly associated with levels of parental hope than with the physical deficits of those children (Kirpalani et al., 2000). Additionally, hope is important to the parents themselves, as it has also been shown to have direct health benefits (Greer, Morris, & Pettingale, 1979; Greer, Morris, Pettingale, & Haybittle, 1990; Miller, 1993; Schmale & Iker, 1966; Ziarnik, Freeman, Sherrard, & Calsyn, 1997). Because parental hope has been shown to impact quality of life and treatment outcomes, understanding the levels of hope in parents of children with chronic illness is of great value to health care professionals. Unfortunately stress theory, which has been a central force in researching how families cope with stressors, has not included hope as a coping mechanism or correlate in stress research (Farran, Herth, & Popovich, 1995).

Statement of the Problem

Hope is a process that deals with areas of rational thought, relationships, experiences, and the spiritual or transcendent realm. Hope can also be seen as an antecedent to coping, as a coping strategy, and as an outcome. As such, it is an important consideration in dealing with patients and their families. This concept has been shown to have a positive correlation with health outcomes and quality

of life. There is little information in the literature regarding the levels of hope in parents with chronically ill children.

Statement of the Purpose

The purpose of this study is to explore the levels of hope in parents of chronically ill children. In addition this research will examine whether any correlation exists between levels of hope in the parents of chronically ill children and their perceived level of disability of the child.

Significance and Justification

Depending on how the term chronic illness is defined, from 4% to 32% of the children in the United States have some type of chronic illness (Jackson & Vessey, 1996; Stein & Silver, 1999). Families caring for these children face added responsibilities that can cause stress and tax family resources. Financial concerns stemming from medications, special equipment, extra childcare costs, and loss of income cause added stress (Eiser, 1993). Living with a child affected by chronic illness can be an emotional drain for the parents and siblings due to the anxiety associated with waiting for the next exacerbation of the condition. Relationships within the family are strained from the lack of time available for recreation and togetherness.

Parents are ultimately responsible for the care of the chronically ill child and bear the burden of coping with added demands associated with the chronic condition. Hope has been described as an antecedent for coping. By measuring hope in the parents of chronically ill children and correlating the perceived level of disability of the child with the levels of hope, the information obtained from

such research might be used to encourage higher levels of hope, improve coping, and consequently enhance quality of life and other beneficial outcomes for the chronically ill children and their families.

The direct benefit of hope to the individual's health is another important consideration for the parents. If the parents' health declines, their ability to care for their child is diminished.

Parental hope has been shown to impact quality of life and health outcomes. Understanding the levels of hope in parents of children with chronic illness is of great value to health care professionals and falls well within the domain of nursing.

Research Questions

- 1) What are the levels of hope in parents of children with chronic illness?
- 2) Is there a correlation between levels of hope in parents of children with chronic illness and the perceived level of disability of the child?
- 3) What, if any, differences are there between the primary caregiver of the child and the spouse in regards to questions 1 & 2?

Definition of Terms

Parents

Parents are defined for this study as the child's legal guardian or guardians.

Child

The term child is defined as an individual between the ages of birth to 18, who resides with, and receives the majority of their sustenance from their parents.

Hope

The following conceptual definition of hope by Farran et al. (1995) is used for this study.

Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way relating to oneself and one's world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present. (p. 6)

For the purpose of this study, hope is expressed as a total score on the Herth Hope Index (HHI) which is based on the global and specific dimensions of hope conceptualized by Dufault and Martoccino in 1985 (Farran et al., 1995).

Chronic Illness

The noncategorical definition of chronic illness covers three domains. First, the condition includes a biological, psychological, or cognitive disorder. Second, the condition must last for at least one year. Lastly, there must be a consequence of the disorder (Stein, Westbrook, & Bauman, 1997). The consequences can be any one of three types, functional limitations, reliance on compensatory mechanisms or assistance, or service use or need beyond that which is considered routine disorder (Stein et al., 1997).

For this study specific conditions/illnesses that fit the above definition were selected. Accordingly, chronic illness is defined as any one of the following disorders: cerebral palsy, epilepsy, asthma, or diabetes.

Perceived Level of Disability

Webster's Dictionary defines disability as "a being physically or mentally disabled". Disable is defined as "to incapacitate physically or mentally." (Lorimer et al., 1995, p. 269). Perceived level of disability is measured from scores assigned by parents to items on sections one and three of the Amount of Assistance Questionnaire (AAQ).

Demographic Variables

Demographic variables of the parents recorded for this study included their gender, age, relationship to the child, and whether or not they were the child's primary caregiver. The age, gender and diagnosis of the child was also included in the demographic questionnaire.

Military status was elicited in the questionnaire for a number of reasons. First, this study was done at a military hospital and the data relating to military status may be of interest to other researchers in the future. Secondly, active duty personnel might have less time available to care for the child. Thirdly, active duty personnel have a stable job and income. Finally, active duty personnel and their dependents have access to a wide variety of social support services and medical care not as readily available to many civilian personnel. One of these

services guarantees that the family will be stationed in an area that has medical facilities capable of managing a chronically ill or severely handicapped family member.

II. REVIEW OF LITERATURE

Chronic illness affects approximately 10.3 million children in the United States. Caring for these children places added demands on not only the child, but the family as a whole. Stress theory states that what effects one member of a family affects all the members of that family (McCubbin & Thompson, 1987). Added stressors related to time, finances, and care giving can take their toll on the ability of the family to successfully cope with the additional demands. This is especially true in the case of parents of a chronically ill child. Because of their position in the family, most of the extra burden falls on the parents. Even though hope has been identified as an element crucial to coping, it has not been included in stress theory, which has guided much of the research in the last couple of decades relating to how people cope with stress (Farran et al., 1995). In addition to hope's relation to coping, parental hope has shown to be positively correlated to quality of life and health outcomes for children.

Issues relating to chronic illness in children, the concept of hope, and studies on the levels and effects of hope were found in the literature. This chapter will discuss the characteristics of hope, the importance of hope, using hope, a conceptual framework for hope, issues related to parenting chronically ill children, and a theoretical link between a child's level of disability and their parents' levels of hope.

Chronic Illness in Children

Numerous authors in the scientific literature, applying varying definitions have examined chronic illness in children. Depending on how chronic illness is defined, estimates of the percentage of children affected by chronic illness range from 4% to 32% (Jackson & Vessey, 1996; Stein & Silver, 1999). Many of the estimates in the literature concerning the prevalence of chronic illness in children were derived from the 1981 and 1988 National Health Interview Surveys, which depended on a disease-specific checklist. By defining chronic illness in the narrow terms of specific illnesses, these estimates were erroneously low (Stein & Silver, 1999). In contrast, the 1994 National Health Interview Survey on Disability Supplement asked questions intended to find out the functional status of the child, dependence on compensatory systems (such as diets, medications, or equipment), and use of other than routine services. Silver and Stein (1999) were able to analyze this data with an instrument based on a non-categorical definition of chronic illness and estimated that in the United States 10.3 million children, or 14.8%, have chronic conditions.

Practitioners must consider stressors, and the family's ability to deal with them, in planning for care (Jackson & Vessey, 1996). Since the parents are most intimately involved in the child's care their health and well-being is a major concern. Should the parents not successfully cope with the added stressors of

their child's chronic illness, it stands to reason that the child's care will suffer. Additional stressors for parents with a child having a chronic illness include, increased financial burdens, social isolation, role overload, physical exhaustion (Eiser, 1993), as well as organizing and coordinating services for their child (Wallace et al., 1997).

Coping behavior has been defined as efforts by an individual or group of individuals, such as a family to manage or decrease demands on the family system (McCubbin & Thompson, 1987). Families can cope by avoidance, elimination, and assimilation (McCubbin & Thompson, 1987). Avoidance would be denying or ignoring the stressor. An active effort to do away with or change the stressor in order to decrease demands on the family would be considered elimination. Assimilation occurs when efforts are made to embrace the demands placed on the family by the stressor and integrate these demands by making changes within the family unit (McCubbin & Thompson, 1987). In the case of parents dealing with caring for a child with a chronic illness, elimination and avoidance can only be used temporarily, if at all. Assimilation is the only coping mechanism that can deal with the situation for the long term. Without an adequate level of hope, Herth (1993) asserts that effective coping may not occur. Unfortunately, hope has not been included as an important variable in the stress/coping paradigm that has guided much health related research in the past twenty years (Farran et al., 1995).

Characteristics of Hope

Hope is a complex, abstract concept that is difficult to define (Gelling, 1999). However, positive anticipation of future events seems to be a common thread in the hope literature (Ballard, Green, McCall, & Logsdon, 1997; Cutcliffe R., 1997; Dufault & Martocchio, 1985; Gaskins & Forte, 1995; Fowler, 1995; Hinds, 1984; Hunt Raleigh, 1992; Kylma & Vehvilainen-Julkunen, 1997; Miller 1983; Post-White et al., 1996; Spencer, Davidson, & White, 1997; Stubblefield & Murray L., 1998). Hope is also associated with having positive emotions (Gaskins & Forte, 1995).

Types and sources of hope are other aspects discussed in the hope literature. Dufault and Martocchio (1985) describe a spherical model for hope. Generalized hope constitutes the inner sphere surrounded by an outer sphere of particularized hope. Generalized hope looks towards a useful future development that is not predetermined, whereas particularized hope is tied to an identified object of hope. These spheres are divided up into equal pie slices by six dimensions of hope, affective, cognitive, behavioral, affiliative, temporal, and contextual. Each dimension of hope has special components that give structure to the experience of hope. As the individual focuses on differing spheres and dimensions of hope, the process of hope for that person is altered.

Analysis of 46 articles, with hope or hopelessness as main themes, published between 1975 and 1993 demonstrated that generalized and particularized hope were concepts common in the hope literature (Kylma & Vehvilainen-Julkunen, 1997). In addition the findings showed that activity has a

two-fold relationship to hope. It is required for hope, but at the same time, hope is required for activity. Hope was also seen as a process that can be affected by the individual, other people, or circumstances.

Fatigue is one factor that has been shown to affect levels of hope. Studies by Herth (1992,1993) and Bunston, Mings, Mackie, & Jones (1995) found significant negative correlation between levels of fatigue and levels of hope. In contrast, hope was positively correlated with education level and income (Bunston et al., 95; Herth, 92). Other elements that have been statistically correlated with hope are locus of control, number of unresolved needs, marital status, concurrent losses, and frequency of worship attendance (Bunston et al., 95; Herth, 92,93; (Vandecreek, Nye,& Herth, 1994). Factors that correlate to levels of hope may be due to their impact on sources of hope.

A qualitative study of 12 adults over age 65, reveals 10 theme clusters for sources of hope (Gaskins & Forte, 1995). The top five themes in order of frequency are spirituality, relationships with others, having one's health, having positive emotions, and anticipating the future. By analyzing the sources of hope, Gaskins and Forte (1995) identified the following essential structure of hope as, "a positive future situation that is experienced in the present. There are special sources of support for one's hope. Participants had hope in the present because they were looking forward to the future" (Gaskins & Forte, 1995, p. 22). This essential structure is still not a concise definition, but it gives dimension to the notion of hope.

Hope was defined by John R. Cutcliffe (1997, p. 330) as, "a multi-dimensional, dynamic, empowering, state of being, that is central to life, related to external help and caring, orientated towards the future and highly personalized to each individual." He arrives at this definition after exploring key themes and dimensions of hope found in the literature to date. With over 50 references, he has thoroughly synthesized a clear and concise working definition. Unfortunately Cutcliffe's definition does not address the impact of unmet expectations. The working definition used for this study comes from the definition Farran et al. (1995) used in their book Hope and Hopelessness: Critical Clinical Constructs. They defined hope as,

Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way relating to oneself and one's world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present. (p. 6)

In 1987, Kaye Herth (1991) used the hope model proposed by Dufault and Martacchio (1985) to construct an instrument to measure hope, the Herth Hope Scale (HHS). Herth combined Dufault and Martacchio's six dimensions of hope to form three; cognitive-temporal, affective-behavioral, and affiliative-contextual. Questions in the HHS were then constructed to elicit a response on a four point, Likert type scale with higher scores denoting higher levels of hope. This instrument was further abbreviated by combining items on the questionnaire that asked questions pertaining to any one of the three domains of hope to be

measured (Herth, 1992). The result is the Herth Hope Index (HHI), which is this instrument used in this study to measure hope.

Measuring Hope with the HHI

The HHI has been used in numerous studies with widely varied populations. In a 1990 study of 30 terminally ill adults, Herth used the HHI to assess hope while evaluating hope fostering strategies. The mean HHI score for these adults was 39.

Further development and psychometric testing of the HHI was accomplished by Herth in 1992 using a convenience sample of 172 ill adults. HHI mean scores for this population was 32.39.

Another population studied with the HHI was family caregivers of terminally ill people. A total of 25 caregivers were assessed with overall mean hope scores of 37 (Herth, 1993).

Kaye Herth teamed up with Christina Nye and Larry Vandecreek for a study that compared levels of hope in three different groups. The first group consisted of community sample of 166 people who were part of a local choral group, a women's service organization, or a Civitan Club. Family members in a surgical waiting room comprised a second group of 141 people. Finally, a third group of 132 patients from a university related hospital was created. Mean hope score for the community group was 40.10, the family members had a mean score of 39.29, and the patient mean hope scores were 39.66(Vandecreek et al., 1994). The differences in the mean hope scores for the three groups were not significantly different.

Importance of Hope

One importance of hope was expressed by Leslie Gelling (1999, p. 34), "Hope is seen as an essential prerequisite to coping during a period of illness." Hope itself can function as an emotion-focused or problem-focused coping strategy and a process of cognitive reappraisal (Farran et al., 1995).

Health related quality of life was reported to be more significantly associated with parental hope than physical deficits of children with spina bifida (Kirpalani et al., 2000). Parental hope has also been shown to be a major positive factor in the survival of burned children (Seligman, MacMillan, & Carroll, 1971).

In contrast hopelessness, which represents opposite expectations on an experiential continuum (Farran et al., 1995), can have negative effects on the health and well being of the individual. A study of 40 women with abnormal pap smears by Schmale and Iker (1966) used hopelessness scores to predict which women would have cervical cancer. Predictions of cancer or no cancer were correct in 31 of 40 patients. Schmale repeated the study in 1971, where accurate predictions were made in 50 of 68 patients (Miller, 1993). In a study of women with breast cancer, hopelessness and stoic acceptance correlated with higher recurrence and death than did denial or a fighting spirit (Greer, Morris, & Pettingale, 1979). This work was extended by two additional studies. A later study confirmed that the correlation continued to 10 and 15 years after surgical treatment (Greer et al., 1990). Survival of renal dialysis patients was shown to be longer with a sense of hopefulness about the future (Ziarnik et al., 1997). If hope

can in fact influence the condition of the caregiver or patient, it falls well within the domain of nursing as a subject of research and intervention.

Using Hope

Nurses as well as other health care providers need to understand that hope can be a powerful force in helping patients and use it in the clinical setting (Miller 1983, Chap. 16). Pamela S. Hinds (1984, p. 359) mirrors this thought in her statement, "Hope is an acknowledged component of the nursing process." Miller (1983, p. 292) states in her book, "Nurses must make a conscious effort to work with patients to display hope for the living or an improved state." Nurses can use hope as an empowering "state of being" to assist their patients and families in achieving their goals (Gaskins & Forte, 1995).

Conceptual Framework

The conceptual framework for exploring hope in this study is the HOPE/GRACT framework suggested by Farran et al. (1995). This framework incorporates the four central attributes of hope. Experiential process is the first attribute and is symbolized by H= Health. The second attribute, relational process is represented by O = Other. P for Purpose symbolizes the spiritual/transcendent process of hope. The fourth and final central attribute of hope, rational thought process, is signified by E = Engaging.

The experiential process deals with the relationship between hope and individual suffering. Hope allows for wider possibilities to be considered during the experience, but past experiences can also provide a basis for hope. Although

the suffering may be caused by a decline in the individual's health status, it can also be tied to the condition of a loved one.

The relational process component takes into account the importance of others in an individual's level of hope. The relationships between friends and family can have a significant impact on hope, in that a high level of hope in one person can inspire hope in another.

Belief in a higher power has been correlated with high levels of hope. The spiritual/transcendental process accounts for the contribution of religious beliefs and faith to high levels of hope.

The last attribute, rational thought process, include strategies like talking to one's self in positive terms and remembering joyful times. Goal setting, goal refinement, and goal refocusing are other approaches that would be included in this attribute. The attribute of rational thought process provides a hope grounded in fact or reality.

In order to allow a more comprehensive assessment of the rational thought process, the acronym GRACT can be used. "G" stands for goals. Goals that motivate the person are a component of hope. "R" signifies resources. This includes social, physical and emotional resources, both from within and from exterior sources. "A" indicates action. Taking action towards meeting goals and continuing to remain an active part of one's situation is integral in maintaining hope. "C" denotes control. The more a person feels in control of their life, the greater their hope. "T" relates to time. Experiences of the past, the sense of the

present, and outlook for the future all interrelate to impact one's perception of hope (Farran et al., 1995).

Measurement of these attributes can give the clinician an overview as to the client's level of hope. If the level of hope is low, coping may be hampered. Assessment of the cause for the low level of hope can discover areas for possible intervention, hope can then be restored, and coping enhanced (Farran et al., 1995).

Link of Level of Disability to Hope

Although review of the literature did not find any studies that directly examined a relationship between the level of disability in chronically ill children and the level of hope in their parents, there are findings that indirectly suggest such a relationship. It is logical to assume that as the level of disability of the child rises, so does the amount of care the child requires, consequently increasing parental stressors. The literature does support the notion that parents of chronically ill children experience a number of added stressors to their lives, which puts them at higher risk for fatigue. Fatigue, in turn, has been shown to have a negative impact on hope (Herth 1992,1993; Bunston et al., 1995).

In a study of mothers of children with diabetes, spina bifida, or cystic fibrosis, 94% of the mothers related being fatigued and stated they did not have enough time to meet their own needs (Stewart et al., 1994). Jensen and Given (1991) found that the caregiver fatigue was related to the impact of caregiving on a persons daily schedule (Jensen & Given A., 1991). Anna Gravelle (1997) found, in her study of parents caring for children with progressive illnesses, that the

challenges of caring for these children greatly increased the mother's risk for exhaustion. Other studies show that mothers of chronically ill children are more likely to be depressed if there is a functional limitation associated with the child's condition (Shepard & Mahon, 2000).

Herth (1993) explored hope in a study of family caregivers of the terminally ill. In her study of 25 caregivers, 20 of them reported high levels of fatigue. Once the data was analyzed, severe interference with sleep and high levels of fatigue correlated to lower levels of hope.

It is interesting to note however, that in this study the level of disability of the care recipient did not show a significant relationship to the caregivers level of hope. Herth's 1993 study may suggest that the level of disability of the care recipient does not affect the levels of hope in the caregiver, but the subjects of her study ranged in age from 23 to 72 years and were terminally ill. The results of her study may or may not reflect how hope is affected when the caregivers are parents and the care recipients are children of age 18 years or younger. Therefore this study will attempt to discern the extent to which hope levels are affected when the care recipient is the caregiver's child.

Schematic Presentation

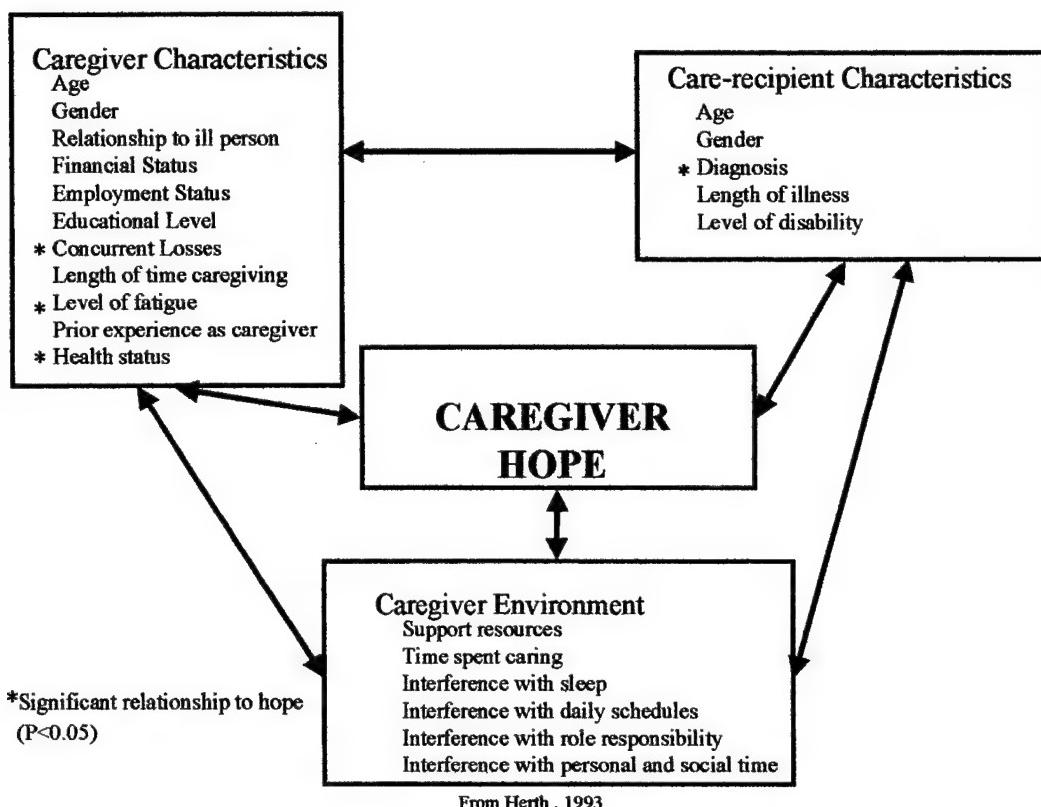


Figure 1 Proposed theoretical model of hope in family caregiver of a terminally ill family member from Herth, 1993

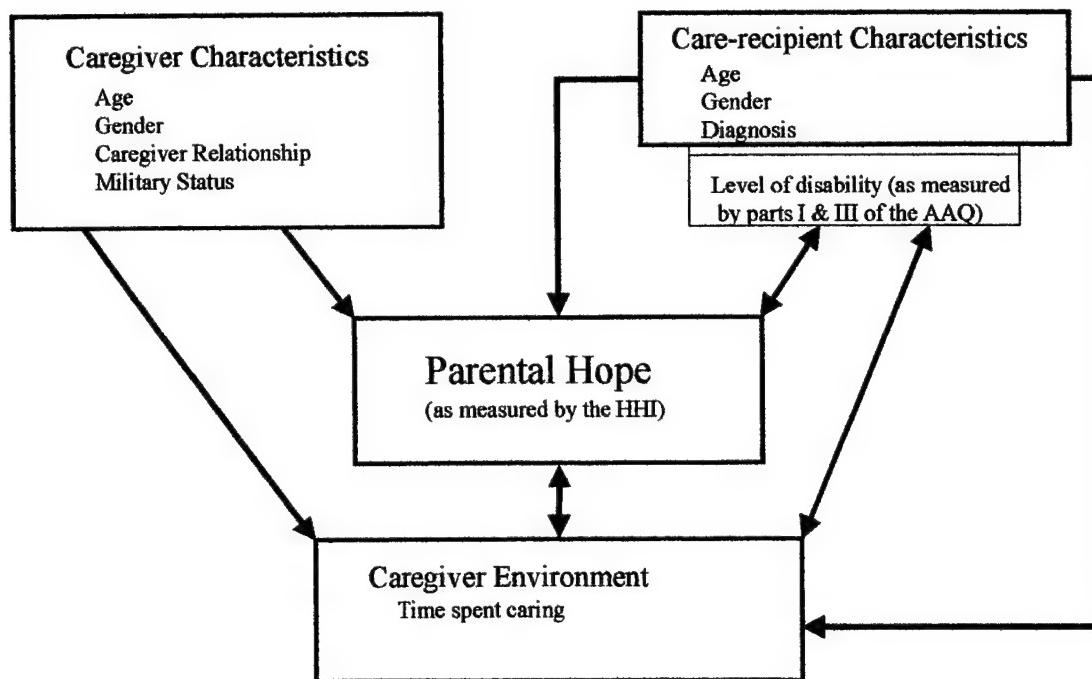


Figure 2 Proposed theoretical model for this study

Assumptions of the Model

The theoretical model for this study assumes foremost that hope is critical to coping in all areas of life. Without hope one has no expectations that circumstances can be influenced to create a favorable outcome, so there is no motivation to attempt change. Consequently, possible options in treating a chronically ill child may not be considered, so quality of care suffers.

Levels of hope are presumed to be influenced by certain characteristics. The amount of time caring for a chronically ill child would logically increase with the level of the child's disability. This, in turn, could produce fatigue in the

caregiver, which has been shown to decrease levels of hope (Herth 1992,1993; Bunston et al., 1995).

Another assumption of the model is that the instruments to measure hope and the child's disability were adequate. Hope is assumed to be qualitatively measured using the HHI, which has been meticulously developed and tested. The model also assumes that part I of the AAQ and selected items in the AAQ part III, used in other studies, adequately measures the level of disability of the child as perceived by the parent.

Summary

Hope is a difficult concept to narrowly define. It has certain characteristics that are commonly associated with it, such as positivism, that it is a process, it leads to and is affected by activity, and it looks to the future with optimism. Hope can have a positive effect on a person's health status and so warrants the attention of nursing. Parents dealing with the factors associated with caring for a child with a chronic illness experience added stress. Hope is a buffer for stress and required for effective coping (Herth, 1993).

The specific sample populations in prior research limits the extent to which one can generalize the results to other populations. Only one study was quasi-experimental. In addition, many of these studies used convenience sampling, which may have introduced bias. Another concern is whether the seriousness of the illness in some of the studies had a negative impact on hope, rather than hope having a positive impact on illness outcome. However, the studies do, at least, suggest a correlation between hope and patient outcome.

Articles dealing with the concept of hope using Meta-analysis and Grounded theory appeared to be thorough. Most of the studies using instruments included validity and reliability information.

Parents of chronically ill children face added burdens and stressors beyond that of normal parenting. Since hope has been shown to be linked with the ability to cope as well as positive health outcomes, understanding the levels of hope in these parents is crucial. This study is being accomplished in order help fill the void of information within the scientific literature regarding this area to date.

III. METHODS

This descriptive-correlational study examined the self-reported level of hope in parents of children with chronic illness. The secondary purpose was to explore the relationship of the child's perceived level of disability, measured by the amount of assistance questionnaire (AAQ), to levels of hope in parents of children with chronic illness. A third purpose was to compare the levels of hope in the primary care giver of the child to the caregiver's spouse to see what, if any, differences exist. Examination of this information may provide health care professionals with an understanding of how parental hope correlates with the level of disability in their chronically ill child. This understanding may in turn give insight to clinicians regarding the impact a child's chronic illness has on their parents, ultimately increasing quality of life and outcomes for these children by accurately identifying the cause for decreased parental hope allowing for hope fostering intervention.

This chapter includes the research design, setting, and population studied. The sampling plan, ethical considerations, instruments used, and data analysis plan are also discussed.

Research Design

A descriptive-correlational study was used to examine self-reported levels of hope in parents of children with chronic illness. The relationship of perceived hope, and the level of the child's disability was also explored. Many

interrelationships in a situation can be identified in a short period of time using a descriptive-correlation research design. Well-defined variables, valid and reliable instruments, and controlled data collection can help control potential bias (Burns & Grove, 1997).

Setting

The setting for the research study was one of the U. S. Air Force's largest medical centers. This 90-bed regional medical center has full Joint Commission on Accreditation for Health Care Organizations (JCAHO) and is affiliated with Wright State University School of Medicine. The medical center serves Region V in the Midwest, with a population of approximately 45,000 beneficiaries.

Population

The population for this study was parents of children with the selected chronic illnesses of asthma, cerebral palsy, diabetes, or epilepsy, receiving care from the participating hospital. The accessible population was those parents who have received care for their children with selected chronic illnesses, seen in the participating medical center in the 6 months previous to the study who were willing to respond to the questionnaire.

Sampling Plan

ICD9 codes, which are used to identify patient diagnosis for medical transcription and billing, were obtained from the participating hospital for children with asthma (493), cerebral palsy (343), diabetes (250), and epilepsy (345), seen within 6 months before the start of the study. Diagnosis codes for the

child could have been a first, second, or third degree diagnosis. The ICD 9 codes were then used to generate a list of candidates for mailing of the questionnaires.

An effort was made to obtain a stratified random sample for mailing in order to have similar representation of each of the conditions selected for this study. However, due to the lack of subjects with diagnoses of cerebral palsy, diabetes, and epilepsy, saturation sampling was used with these diagnoses and randomization was used to select the remainder of surveys to be mailed from the asthma group. A total of 304 surveys were distributed with a response rate of 19% (58). Two surveys, coded to allow identification of surveys relating to the same child, were mailed to each address in hopes of obtaining responses from both parents. Included with the surveys was a cover letter and self-addressed, postage paid envelope.

A convenience sample was obtained by return of the surveys by those parents of children with one of the identified chronic illnesses desiring to participate in the study. Convenience sampling was chosen because of time, financial constraints, and ease of obtaining the sample.

Ethical and Human Subject Considerations

Confidentiality was assured in that no personal identifying information was asked for in the questionnaire. Coding of the surveys only assured that surveys regarding the same child were paired. In no way was the coding linked to the names or addresses of the respondents. The cover letter explained the reason for the research, gave instructions on filling out the questionnaires, and assured the subjects that participation or lack of participation would have no

impact on medical care. There were no anticipated negative consequences and the only positive consequence would be possible future benefits to other parents and patients from information gained by the study and the satisfaction in the respondents for helping a graduate student finish his degree.

Institutional Review Board (IRB) review for the study was completed at Wright State University, and the participating hospital before the study was started. Consent to participate in the study was implied by completion and return of the survey.

Data collected by the researcher was analyzed at the Wright State University Statistical Consulting Center. The results of the study were made available to each participating facility and to any individual upon request. All returned surveys were considered the property of the principal investigator.

Instruments

Herth Hope Index

The Herth Hope Index (HHI) was used to measure hope for this study. The HHI was chosen for its short length, validity and reliability, and ease of administration. Since 1990 this instrument has been in 32 different study areas with Chronbach Alpha's ranging from 0.81 to 0.89, by over 211 faculty researchers, clinicians, PhD students, and Master's students (K. Herth, personal communication, August 24, 2001).

The instrument consists of 12 items with four possible responses using a Likert type scale. It is a pencil and paper instrument filled out by the subject. Reading level for the instrument is sixth grade according to the Flesch

Readability Formula (Herth, 1992). The HHI is abbreviated form of the Herth Hope Scale (HHS) developed by Kaye A. Herth (1992) to provide a concise, simple, method of measuring hope that has acceptable psychometric properties.

Evaluation of the HHI was undertaken using 172 adults with differing health status, background and settings (Herth, 1992). Two separate review panels evaluated face and content validity. The first panel examined the congruence of the HHI items with the conceptual definition of hope, clarity and readability of the questions, and ease of understanding of the instructions. Members of this four-person panel were university members highly experienced in development of research instruments.

The second panel consisted of six nurse clinicians and six clients diagnosed with acute, terminal, or chronic illness. Face validity, language, clarity, and simplicity of the HHI were evaluated by this group (Herth, 1992).

The Herth Hope Scale (HHS, the Existential Well-Being Scale (EWS) and the Nowotny Hope Scale (NHS) were administered along with the HHI to appraise content validity. Acceptable Chronbach's alphas for all validating instruments ranged from 0.88 for the EWS to 0.95 for the HHS.

The HHI showed a Chronbach's alpha of 0.97. Correlation between the HHI and all of the criterion measures was high, ranging from 0.81 for the NHS to 0.92 for the HHS. Test -retest correlation for the HHI was 0.91 (Herth, 1992). The HHI has also been used and evaluated in a study of family caregivers of terminally ill patients. Chronbach's alpha coefficients were collected at three

different points in the study to measure internal consistency and ranged from 0.89 to 0.91 (Herth, 1993).

Permission to use the HHI, along with scoring information, was obtained in writing from Dr. Herth. Scoring of the HHI is done on an ordinal scale from 1 (strongly disagree) to 4 (strongly agree). Questions one and six are reverse scored. Range of possible scores is 12 to 48 with higher scores correlating with higher levels of hope.

The study of hope in family caregivers of terminally ill people by Herth (1993), mirrors the intent of this study, in that the levels of hope being studied are in caregivers, not in the patients themselves. Herth noted that other studies have suggested that the levels of hope in close family members may have a significant impact on the patient's level of hope, but there were no studies in the literature at that time that examined the caregiver's level of hope directly. The validity of Herth's 1993 study findings was confirmed by discussions with five of the family caregivers after the study.

Amount of Assistance Questionnaire

Level of disability was measured by the AAQ, which focuses on the amount of effort needed and time spent by the child to complete activities of daily living (ADL) along with other indicators of assistance required. Michael Msall (1996) piloted the AAQ instrument during a study in 1994 to examine the amount of assistance needed by children with disabilities. The AAQ was selected for this study because it addresses the three domains of a noncategorical definition for chronic illness: functional limitations, dependence on

compensatory mechanisms, and service use or need beyond routine care (Stein & Silver, 1999).

The questionnaire contains 33 questions in 3 different sections. A Part I focuses on developmental skills and asks parents to compare their child's development in motor ability, language, performing ADLs, play, and other activities to other children of the same age. Part II deals with specialized therapies and developmental progress. Questions in this segment identify types of therapy used and the parent's perception of how the child is progressing. Part III addresses activities of daily living. In this section the amount of time and assistance needed by the child is compared to other children of the same age for eating, dressing, toileting, and locomotion. Questions regarding the use of adaptive equipment, and total time of adult supervision needed per day are also included in Part III.

The AAQ does not produce a total score. It is used to identify areas in which the child does not perform as well, requires more assistance, or more time to complete activities than do other children the same age. However, composite scores for selected sections of the AAQ can, and have been used in other studies, in order to correlate levels of disability with other variables (Azaula et al., 2000; Msall & Tremont, 1999; Ottenbacher et al., 2000). Ages of children evaluated by their parents, or teachers, using the AAQ have ranged from 11 months (Ottenbacher et al., 2000), to 16 years (Azaula et al., 2000).

Reliability and validity for the AAQ was examined in a study of 205 children with developmental disabilities (Ottenbacher et al., 2000). The most

common medical conditions of the subjects included cerebral palsy, Down syndrome, epilepsy, prematurity, spina bifida, and other genetic disorders. Test-retest reliability of the AAQ ranged from 0.82 to 0.97. Validity was established by a correlation value of $r = 0.91$ with the Functional Independence Measure for Children (WeeFIM), an established functional assessment for children.

Permission to use the AAQ was sought from Dr. Msall. His research assistant, Michelle Tremont, stated that the instrument was not under copyright and anyone was free to use it (personal communication, December 4, 2001).

After consultation with the Dr. Fulton, Thesis Chair for this study, and DeAnne Colvard French from the Wright State University Statistical Consulting Center, the decision to omit part II of the AAQ from the survey to be mailed was made. Part II of the AAQ deals mainly with specialized therapies and it was felt would add extraneous variables that would complicate data analysis beyond the scope of this study.

Responses to Part I of the AAQ were totaled as a composite score with a possible low of 15 to a high of 75 with the higher score indicating higher functioning with less assistance needed.

The first 7 questions from Part III of the AAQ were also combined into a single score, then reverse scored to allow the score to be interpreted the same as Part I, with higher scores denoting less assistance needed. Scores for Part III of the AAQ could range from a high of 35 to a low of 7.

The questions relating to use of adaptive equipment in Part III of the AAQ were not included in data analysis because the first was a yes or no question

regarding use of adaptive equipment with the second asking how much assistance the child needed using the equipment. The resulting data would have been skewed due to the high "no" response rate of over 70%, coupled with the associated "none" response for assistance required to use the equipment.

Procedures for Data Collection

The researcher obtained the list of addresses for children diagnosed with the selected medical conditions from the participating hospital. The surveys, a cover letter, and self-addressed postage paid return envelopes, were enclosed in postage paid envelopes. Mailing labels were processed by the participating hospital and given to the researcher. The mailing labels were affixed to the envelopes and mailed by the researcher. Those parents who chose to participate filled out the questionnaires and mailed them to the researcher using the self-addressed postage paid return envelopes. The questionnaires were collected by the researcher at a general delivery post office box obtained specifically for the purpose and coded into a Microsoft Excel spread sheet. The coded data was then given to the Wright State University Statistical Consulting Center Statistical for analysis.

Summary

This descriptive-correlational study examines the levels of hope in parents of children with chronic illnesses and possible correlation with the parents' perceived level of disability of their child. Measurement of parental hope was accomplished using the HHI and the level of the child's disability was determined using the AAQ.

IV. ANALYSIS OF DATA

Statistical analysis was performed by the Wright State University Statistical Consulting Center using SPSS version 10.1 on data obtained from 54 surveys. Of the 304 surveys sent, 58 were completed and returned to the researcher for a response rate of 19%. Of the 58 surveys collected, a total of four were excluded from the data analysis. One was excluded for lack of information regarding the child's illness with a statement that their child was not chronically ill. Another survey was excluded due to failure to fill out any of the survey except for demographic information. The other two surveys not included in the analysis had exactly duplicated the survey information, including personal demographics, from the paired survey.

Missing data from the AAQ or the child's demographics was filled in during data entry for four of the surveys by using corresponding data from the paired survey. In two instances identical data was omitted from the AAQ in both of the paired surveys or there was no paired survey available. Data in these cases was entered by using the average value of the surrounding responses.

A total of four surveys were returned with none of the diagnoses listed for the child marked and another diagnosis written in. These were included in the data because the diagnoses given were consistent with the noncategorical definition of chronic illness and had probably been coded as cerebral palsy in the

hospital's data base. These were listed under autism/mental retardation in the analysis.

Demographic Profile of Sample Group

Age of the respondents were broken into categories of age in years from <20, 21-30, 31-40, 41-50, and >50. No respondents were in the <20 category, five were between 21 and 30 years old, 23 fell within the 31 to 40 age category, 22 were included in the 41 to 50 group, and only four were over 50. Female respondents dominated the demographics compromising 57.4% of the sample (N = 31). Most of those included in the study, 48.1%, were military dependents. Eventhough retired military was not a category included in the survey, seven respondents (13%) identified themselves as such by adding it to the demographic sheet. All but one of the respondents, who was the child's private nurse, classified themselves as a parent or legal guardian. Those who indicated they provided the most care to the child constituted 53.7% (N=29) of the respondents. On two of the surveys regarding the same child, the question regarding who cares for the child a majority of the time was left blank. The child was put in the cares for self category due to his advanced age of 17 years.

Category	Frequency	Percent
Parent age		
21-30	5	9.3
31-40	23	42.6
41-50	22	40.7
>50	4	7.4
Parent Gender		
Male	23	42.6
Female	31	57.4
Military Status		
Active Duty	17	31.5
Dependent	26	48.1
Civilian	4	7.4
Retired Military	7	13.0
Parent/Guardian		
Yes	53	98.1
No	1	1.9
Gives Most Care		
Child cares for self	2	3.7
I do most care	29	53.7
Spouse does most care	23	42.6

Table 1 Demographic Profile for Respondents

The age of the affected child was broken into years of age categories; <1, 1-5, 6-12, and >12. Ages 1-5 and 6-12 each compromised 37% of the sample used. Most of the children were male, 61.1%. Children with asthma made up 44.4% of the sample. Cerebral palsy was the next most common disorder at 22.2% with 8 of those (14.8% of the total sample) also having a secondary diagnosis of

epilepsy. Diabetes and epilepsy were equally represented with 13% each. The added category of autism/mental retardation constituted 7.4% of the sample.

Category	Frequency	Percent
Child's Age in Years		
1-5	20	37.0
6-12	20	37.0
>12	14	25.9
Child's Gender		
Male	33	61.1
Female	21	38.9
Child's Illness		
Asthma	24	44.4
Cerebral Palsey	12	22.2
Diabetes	7	13.0
Epilepsy	7	13.0
Secondary diagnosis of Epilepsy	8	14.8

Table 2 Demographic Profile for Chronically Ill Child

Research Question 1: What are the levels of hope in parents of children with chronic illness?

Scores on the HHI ranged from a low of 32 to a high of 48. The most frequent scores were 47 and 48 accounting for 14.8% and 16.7% of the responses respectively. The mean score for the HHI was 41.93 with a median of 42 and a standard deviation of 5.098. This information is demonstrated in figure 3.

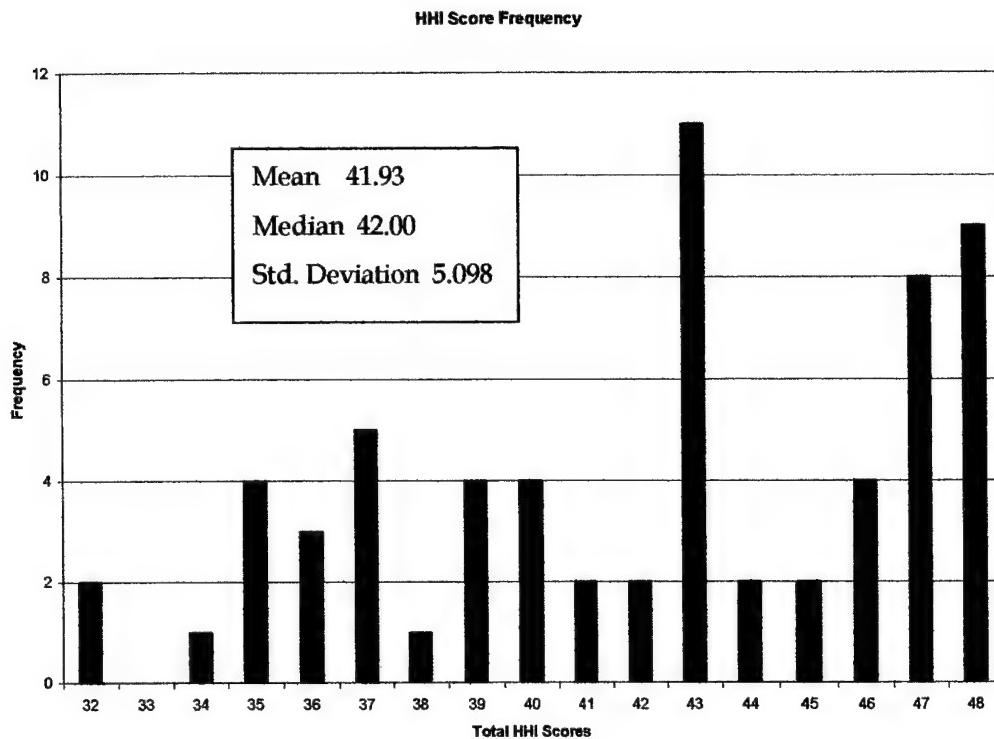


Figure 3 HHI Scores

Research Question 2: Is there a correlation between levels of hope in parents of children with chronic illness and the perceived level of disability of the child?

In order to answer the second research question, total scores for the AAQ part I, the first 7 items from part III of the AAQ, and the total time of supervision needed per day were tabulated. These scores were first analyzed separately, then in aggregate using Pearson's Correlation Coefficient.

Values for Part I of the AAQ ranged from 15 (child is significantly behind in all aspects compared to same age peers) to 75 (child is significantly ahead in all categories). These values were then compared to the total HHI scores to determine what, if any correlation existed. No statistically significant relationship was found between total scores from Part I and HHI scores.

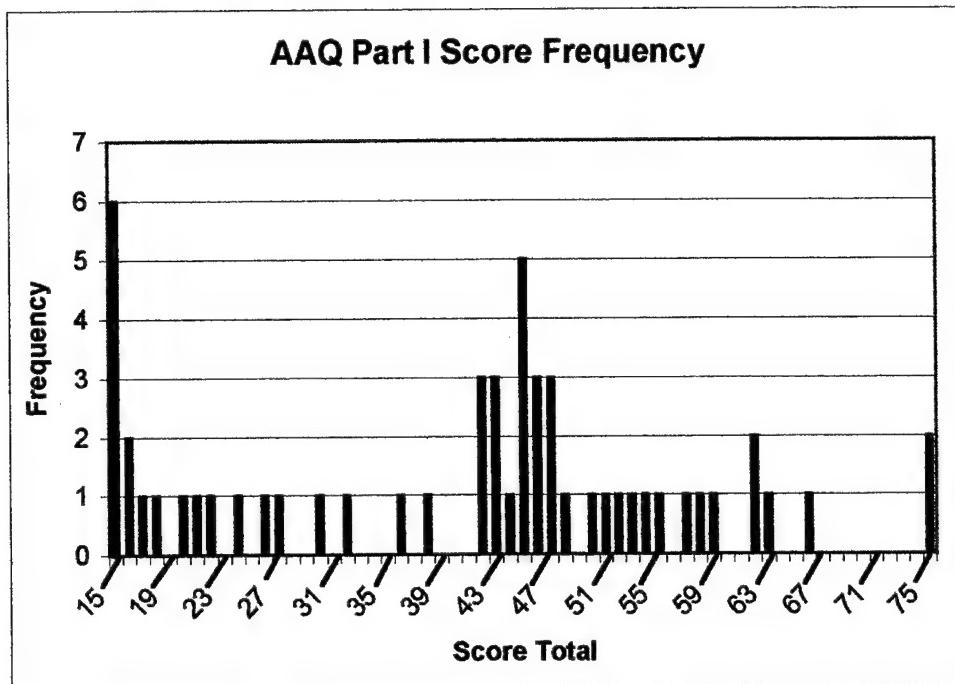


Figure 4 Total Scores AAQ Part I

Total scores for the first 7 items from Part III of the AAQ ranged from 7 to 35. These items were reverse scored during analysis so that interpretation of the scores would be the same as that for the AAQ Part I, in that high scores equated to lower functioning and greater assistance needed. The total score for the first 7 items for the AAQ part III were then compared to the total HHI scores using Pearson's Correlation Coefficient to search for a statistically significant correlation. None was found.

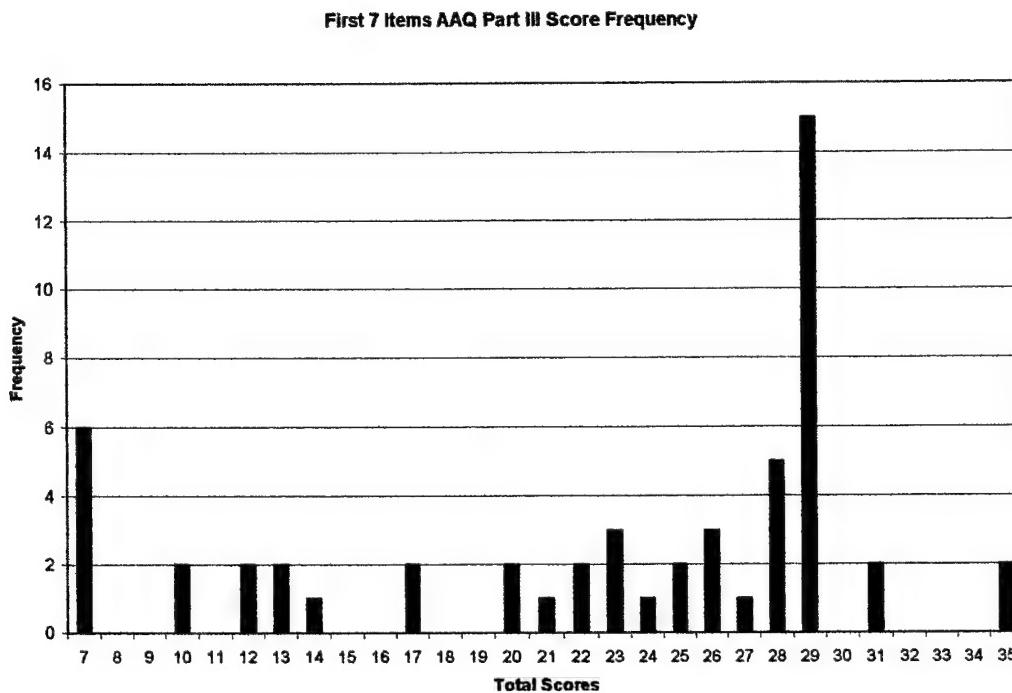


Figure 5 Total Score first 7 Items AAQ Part III

The time of adult supervision and assistance required by the child was also analyzed for correlation to levels of hope. Amount of time required was reported in categories; >12 hours was scored as '5', 8-11 hours scored as "4, 5-7 hours scored as '3', 3-4 hours scored as '2', and 1-2 hours scored as '1'. For respondents leaving this section blank or writing in an answer of less than 1 hour, their responses were scored as 0. Comparison of these values to the HHI scores utilizing Pearson's Correlation Coefficient revealed no significant relationship.

	Mean	Std. Deviation	N
Total score for AAQ Part 1	40.30	16.74	54
Total score for first 7 items on AAQ Part III	22.59	8.621	54
Time per day for assistance	2.56 (between 3-4 and 5-7 hours)	2.08	54
Total HHI score	41.93	5.098	54

Table 3 Whole Group Means

Correlations					
		total score for aaq part 1	total score for first 7 items on aaq3	time per day	total hhi score
total score for aaq part 1	Pearson Correlation	1	.837**	-.701**	.142
	Sig. (2-tailed)	.	.000	.000	.304
	N	54	54	54	54
total score for first 7 items on aaq3	Pearson Correlation	.837**	1	-.824**	.225
	Sig. (2-tailed)	.000	.	.000	.102
	N	54	54	54	54
time per day	Pearson Correlation	-.701**	-.824**	1	-.140
	Sig. (2-tailed)	.000	.000	.	.312
	N	54	54	54	54
total hhi score	Pearson Correlation	.142	.225	-.140	1
	Sig. (2-tailed)	.304	.102	.312	.
	N	54	54	54	54

**. Correlation is significant at the 0.01 level (2-tailed).

Table 4 Whole Group Correlations

Finally, scores for the AAQ Part I, the first 7 items of the AAQ Part III, and the total time of adult supervision required were combined into a single composite score then compared to the HHI score using Pearson's Correlation Coefficient for possible correlation. The combined scores had a possible range of 22-155, with lower numbers indicating lower functioning with more assistance required. The scores ranged from 35 to 110 with a mean of 68.31 and a standard

deviation of 20.263. Comparison with total HHI scores revealed no statistically significant correlation.

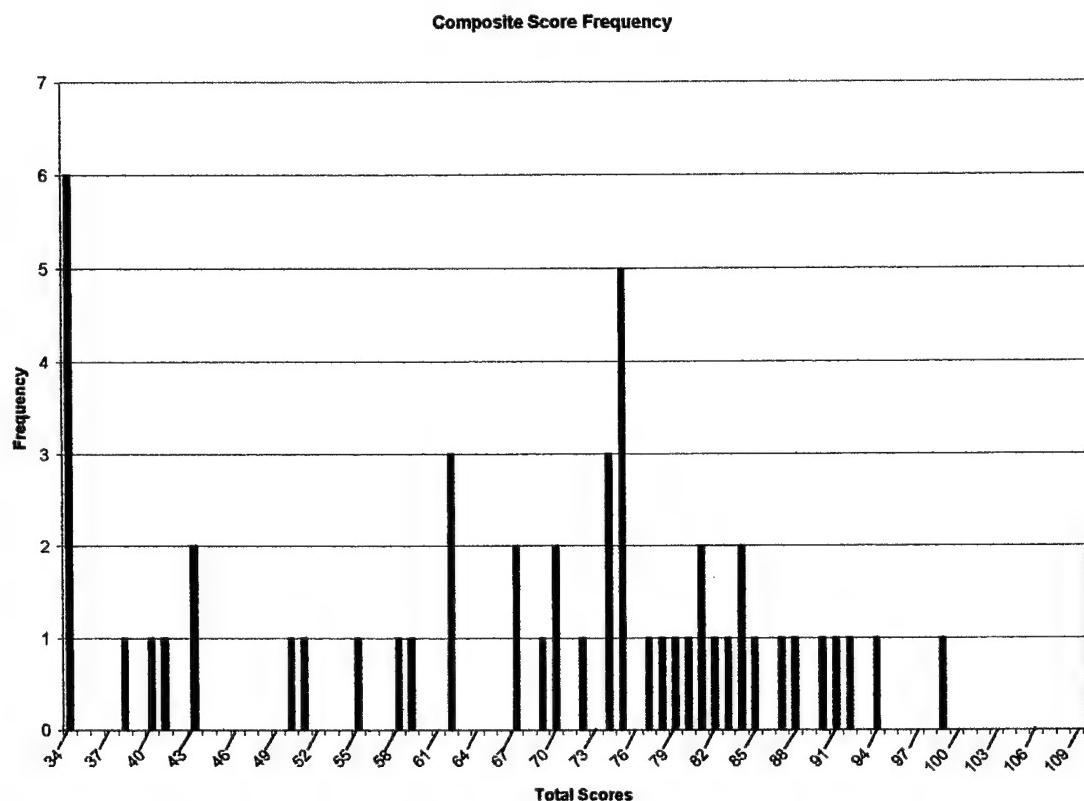


Figure 6 Composite Score Frequencies

total hhi	Pearson		total sum aaq1 & 3, time per
	Sig. (2-tailed) N	total hhi 54	.216 54
total sum for aaq1 & plus time per day	Pearson Sig. (2-tailed) N	.171 .216 54	1 .54

Table 5 Composite Score Correlation

Research Question 3: What, if any, differences are there between the primary caregiver of the child and the spouse in regards to research questions 1 & 2?

In order to answer the last research question of this study the data was split into 2 groups, the “I do most of the care” and the “My spouse does most of the care”. Each of these groups was isolated and the data analyzed in the same fashion as in research questions 1 & 2.

In regards to research question 1 the “I do most of the care” (IDMC) group ($N=29$) had a mean HHI score of 41.97 with a standard deviation of 4.77. The “My spouse does most of the care” (SDMC) group had 23 respondents, a mean HHI score of 41.35 and standard deviation of 5.474. There was no statistical difference between the 2 groups in regards to mean HHI scores.

Regarding research question 2, the total number of respondents in each group remained the same as previously mentioned. The IDMC group had a mean score for the AAQ Part I of 39.97, 22.93 for the first 7 items on the AAQ Part III, time of adult supervision and assistance required by the child 2.59, and a mean HHI score of 41.97. No significant relationship was found between the AAQ Part I score, the total score of the first 7 items on the AAQ Part III, or time of supervision required, and total HHI scores.

Descriptive Statistics

	Mean	Std. Deviation	N
total score for aaq part 1	39.97	15.840	29
total score for first 7 items on aaq3	22.93	7.644	29
time per day	2.59	2.062	29
total hhi score	41.97	4.770	29

Table 6 Statistics for IDMC Group

Correlations

		total score for aaq part 1	total score for first 7 items on aaq3	time per day	total hhi score
total score for aaq part 1	Pearson Correlation	1	.791**	-.600**	-.032
	Sig. (2-tailed)	.	.000	.001	.868
	N	29	29	29	29
total score for first 7 items on aaq3	Pearson Correlation	.791**	1	-.763**	.147
	Sig. (2-tailed)	.000	.	.000	.447
	N	29	29	29	29
time per day	Pearson Correlation	-.600**	-.763**	1	-.067
	Sig. (2-tailed)	.001	.000	.	.730
	N	29	29	29	29
total hhi score	Pearson Correlation	-.032	.147	-.067	1
	Sig. (2-tailed)	.868	.447	.730	.
	N	29	29	29	29

**. Correlation is significant at the 0.01 level (2-tailed).

Table 7 Correlations for IDMC Group

Analysis for the IDMC group using composite scores found a mean score of 68.34 with a standard deviation of 19.072. No statistically significant correlation to total HHI score was discovered.

Correlations

		total hhi score	total sum for aaq1 & 3, plus time per day recoded
total hhi score	Pearson Correlation	1	.010
	Sig. (2-tailed)	.	.958
	N	29	29
total sum for aaq1 & 3, plus time per day recoded	Pearson Correlation	.010	1
	Sig. (2-tailed)	.958	.
	N	29	29

Table 8 IDMC Composite Score Correlation

Those in the SDMC group had a mean score for the AAQ Part I of 37.70, 21.09 for the first 7 items on the AAQ Part III, time of adult supervision and

assistance required by the child was 2.74, and a mean HHI score of 41.35. Again, no significant relationship was found between the AAQ Part I score, the total score of the first 7 items on the AAQ Part III, or time of supervision required, and total HHI scores.

Descriptive Statistics

	Mean	Std. Deviation	N
total score for aaq part 1	37.70	15.461	23
total score for first 7 items on aaq3	21.09	8.575	23
time per day	2.74	2.094	23
total hhi score	41.35	5.474	23

Table 9 Stats for SDMC Group

Correlations

		total score for aaq part 1	total score for first 7 items on aaq3	time per day	total hhi score
total score for aaq part 1	Pearson Correlation	1	.860**	-.782**	.138
	Sig. (2-tailed)	.	.000	.000	.531
	N	23	23	23	23
total score for first 7 items on aaq3	Pearson Correlation	.860**	1	-.872**	.176
	Sig. (2-tailed)	.000	.	.000	.423
	N	23	23	23	23
time per day	Pearson Correlation	-.782**	-.872**	1	-.107
	Sig. (2-tailed)	.000	.000	.	.628
	N	23	23	23	23
total hhi score	Pearson Correlation	.138	.176	-.107	1
	Sig. (2-tailed)	.531	.423	.628	.
	N	23	23	23	23

**. Correlation is significant at the 0.01 level (2-tailed).

Table 10 Correlations for the SDMC Group

Correlations

		total hhi score	total sum for aaq1 & 3, plus time per day recoded
total hhi score	Pearson Correlation	1	.157
	Sig. (2-tailed)		.476
	N	23	23
total sum for aaq1 & 3, plus time per day recoded	Pearson Correlation	.157	1
	Sig. (2-tailed)	.476	
	N	23	23

Table 11 SDMC Composite Score Correlation

Analysis for the SDMC group using composite scores showed a mean score of 64.65 with a standard deviation of 18.821. There was no statistically significant correlation to total HHI score.

A final comparison of the differences between HHI scores for the iDMC and SDMC groups was done using a one way ANOVA with 'who does most care' as the dependent variable & HHI score as the independent variable. The results of the one-way ANOVA was $F=.563$ and a p-value of .884, showing no significant difference.

Who does most care		ANOVA			
	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	3.061	15	.204	.563	.884
Within Groups	13.772	38	.362		
Total	16.833	53			

Table 12 ANOVA Analysis of "Who Does Most Care" Groups

Summary

This chapter discussed analysis results of data from 54 parents of chronically ill children. Data analysis was conducted by the Wright State Statistical Consulting Center using SPSS version 10.1. Hope levels obtained through use of the HHI were tabulated then analyzed for possible correlation to level of disability measured by the AAQ. Discussions of these results are found in chapter V.

V. DISCUSSION

This study helps to further validate the theoretical knowledge of hope, explores the relationships between perceived disability of the child and parental hope, and provides insight that can aid clinicians in relating to parents of chronically ill children.

Summary

A thorough review of the scientific literature uncovered information on chronic illness in children, the concept of hope, studies on the levels and effects of hope, and the issues facing parents of chronically ill children. However, there was a dearth of information regarding levels of hope in parents of chronically ill children.

A strategy to collect data on the levels of hope in parents of chronically ill children and the levels of disability of the children was formulated. Instruments to measure self reported levels of hope in adults and level of disability in children that could be mailed out in survey form were found and utilized for the present research. IRB approval was obtained by Wright State University and the participating hospital. Surveys were mailed to perspective subjects.

Of the 304 surveys mailed, 58 were returned. A total of four surveys were excluded from analysis due to missing data. Analysis of the data were carried out by the Wright State University Statistical Consulting Center using SPSS version 10.1 and given to the principal investigator.

Discussion of the Findings

Research Question 1: What are the levels of hope in parents of children with chronic illness?

The mean hope scores of 41.93 for this study were slightly higher than other studies using the HHI. The closest mean HHI score found from other studies was that of 40.10 from the community group study by Vandecreek, Nye and Herth (1994). At first glance this would indicate that the respondents in this study have a relatively high level of hope. This higher level may be attributed to the stable income, secure job, and services available through the military system. On the other hand, since the surveys were mailed, it is possible that those who had lower levels of hope did not have the energy or motivation to respond.

Research Question 2: Is there a correlation between levels of hope in parents of children with chronic illness and the perceived level of disability of the child?

Analysis of the data using Pearson's Correlation Coefficient showed no significant correlation between the levels of hope in the respondents or the level of disability, regardless of whether the scores on the AAQ were scored separately or as an aggregate. These results suggest that levels of hope in parents of chronically ill children are not significantly affected by the level of their child's disability. Therefore, should a clinician suspect that a parent has lower levels of hope, the assumption should not be made that it is merely due to the fact they have a severely chronically ill or disabled child. Further exploration regarding other possible factors that might be negatively their levels of hope would be needed.

Research Question 3: What, if any, differences are there between the primary caregiver of the child and the spouse in regards to research questions 1 & 2?

No statistical difference was uncovered in regards to which parent cared for the child the most and levels of hope. This finding has similar implications to those from research question 2. Should a parent manifest lower levels of hope, it should not be assumed that the low levels of hope are related to caring for a disabled child. Other possible causes for the lack of hope must be explored.

Assumptions

Certain assumptions were made while conducting this study. Hope was assumed to be antecedent to coping. It was assumed that the Herth Hope Index adequately measured hope. The Amount of Assistance Questionnaire was assumed to adequately measures the parents' perceived level of disability in their child. Lastly, truthful answering of the survey questions by the respondents was assumed.

Limitations

The convenience sampling used may exclude those persons who have lower levels of hope because they may lack motivation to participate. Convenience sampling may also introduce bias through self selection of those most interested in participating in a study. Persons who chose to participate in the study may have significant differences from those who did not.

Confined setting, sample size, and narrow population limit applicability of the study. Most of the respondents (more than 92%) were affiliated with the military, which provides members with many benefits that are not available to a

large portion of the civilian populace. Parents of children with different chronic illnesses than those surveyed in this study or in other settings may have different responses.

Even though the total amount of time required for assisting or supervising the chronically ill child was elicited in the AAQ Part III, how much of that time was given by the survey respondent was not collected. The demographic questionnaire did ask the respondent if he or she cared for the chronically ill child a majority of the time, compared to their spouse or significant other, but did not ask for how much time was actually spent with the child. Since some families hire nurses or attendants to help care for severely handicapped or medically challenging children, the amount of time the respondent actually spent caring for the child may not have been accurately represented.

Other variables that may account for lower levels of hope were not measured. How long the parents have been dealing with the child's condition may change their perception. When the parents are initially confronted with the reality of a severely handicapped child, they may perceive a number of losses; the loss of a "normal child", the loss of future dreams for the child, the loss of future personal opportunities. Concurrent losses, real or perceived, negatively impact levels of hope (Herth, 1993). However, it is likely that after a certain length of time the family adapts and the situation of caring for a chronically ill child becomes part of "normal" life.

There may be a difference between perceptions of parents with children having long periods of routine care, but have intermittent exacerbations that are

life threatening and / or require hospitalizations. In these cases normalization may be difficult to achieve. Visibility of the child's condition could also impact the parent's perception and affect levels of hope. Pretending that the child is not affected by chronic illness might be a coping mechanism, in some, used to bolster levels of hope. However, the more obvious the disability of the child, the harder it is to deny that anything is wrong.

Another variable that could have an impact on levels of hope that was not measured was marital discord. Marital strife can lead not only to high levels of anxiety and stress, but also strain finances. A couple that has worked previously as a team in managing the issues surrounding the child's condition may split up and cease to work together. The resultant feelings of abandonment and isolation have been shown to hinder hope (Herth, 1990).

Implications/Recommendations

Hope is a many faceted concept with numerous factors interplaying to effect its levels. Results of this study indicates that the child's level of disability did not, on its own, significantly affect the levels of hope in the parents. Therefore, should the clinician encounter a parent with low levels of hope, with a severely disabled child, it would be wrong to assume that the main cause was that their child is seriously handicapped. In this instance more assessment to ascertain the true cause of their low hope levels would be warranted.

Also, more needs to be known in regards to what factors have major impacts on parental hope, especially in the arena of chronic illness in children. Other variables that may impact hope, such as length of illness, marital discord,

and the visibility of the child's condition, need to be explored. Additional research in this domain is needed to expand current knowledge, validate or disprove conclusions of earlier studies, and piece together the complex interrelation of the issues impacting families with chronically ill children.

APPENDICES

Appendix A: Wright State University IRB approval

RESEARCH INVOLVING HUMAN SUBJECTS

55

SC# 2580

ACTION OF THE WRIGHT STATE UNIVERSITY
SCREENING COMMITTEE
Assurance Number: M-1021; ID No. 01NR

Title: '*Levels Of Hope In Parents Of Chronically Ill Children*'

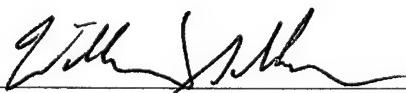
Principal Investigator: Perry A. Carlson, P.I., Student
Janet S. Fulton, Ph.D., Fac. Adv.

Department: College Of Nursing & Health

The Institutional Review Board Screening Committee has approved the use of human subjects on this proposed project with conditions previously noted. The conditions have now been removed.

REMINDER: FDA regulations require prompt reporting to the IRB of any changes in research activity, changes in approved research during the approval period may not be initiated without IRB review (submission of an amendment), and prompt reporting of any unanticipated problems (adverse events).

NOTE: This approval has been assigned an "SC" number in our system, which means it has been approved by the Screening Committee for a protocol involving no more than minimal risk.



Signed Coordinator, WSU-IRB

Screening Committee Date: February 15, 2002

IRB Meeting Date: February 25, 2002

This approval is effective only through: February 15, 2003

To continue the activities approved under this protocol you should receive the appropriate form(s) from Research and Sponsored Programs (RSP) two to three months prior to the required due date. If you do not receive this notification, please contact RSP at 775-2425.

ACTION OF THE WRIGHT STATE
UNIVERSITY
SCREENING COMMITTEE
Assurance Number: M-1021; ID No. 01NR

Title: '*Levels Of Hope In Parents Of Chronically Ill Children'*

Principal Investigator: Perry A. Carlson, P.I., Student
Janet S. Fulton, Ph.D., Fac. Adv.

Department: College Of Nursing & Health

The Institutional Review Board Screening Committee has approved this amendment with conditions previously noted. The conditions have been removed.

REMINDER: Federal regulations require prompt reporting to the IRB of any changes in research activity [changes in approved research during the approval period may not be initiated without IRB review (submission of an amendment)] and prompt reporting of any unanticipated problems (adverse events).



Signed

Coordinator, WSU-IRB

Screening Committee Date: April 12, 2002

IRB Meeting Date: May 20, 2002

Appendix B: Participating Hospital IRB approval

3 April 2002

MEMORANDUM FOR CAPT PERRY CARLSON

FROM: 74th MDOS/SGOA
Clinical Investigations
4881 Sugar Maple Drive
Wright-Patterson AFB OH 45433-5300

SUBJECT: Proposed Protocol

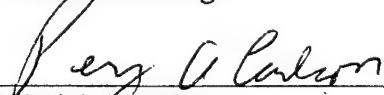
1. The protocol you submitted, "Levels of Hope in Parents of Chronically Ill Children," was reviewed via expedited review and approved by the Chair of the Institutional Review Board (IRB) of Wright-Patterson Medical Center on 8 March 2002. The Commander of Wright-Patterson Medical Center has also reviewed the protocol. It was determined to be exempt and has been assigned file number FWP20020016E. You may now begin your study.
2. Progress reports will be due annually. You will receive a reminder 45 days in advance when your report is due. If you complete your study prior to April 2003 a final report may be completed.
3. Any changes to the study must be submitted to the Clinical Investigations office for approval prior to initiation.
4. Any unanticipated major adverse reactions or other medical misadventures must be reported immediately to the department chairperson, the Chief of Medical Staff, the Clinical Investigations Coordinator and ultimately the commander IAW AFI 40-402. Such events will also need to be summarized in the subsequent progress report.
5. If you anticipate separating from the Air Force or changing assignments before the protocol is completed, you must notify the Clinical Investigations Office as soon as this is known. You will be required to either formally close the protocol, or to have another investigator take over the study. The latter process requires nomination by the flight commander, submission of a curriculum vitae, and approval by the Institutional Review Board.
6. Please indorse below and return to Clinical Investigations. I hope that your study will prove to be a worthwhile experience for you. Let us know if there is any way we can assist you.


DEBBIE BACHMAN
Clinical Investigations Coordinator

1st IND

TO: SGOA/Clinical Investigations

Noted/Acknowledged



Principle Investigator



Date



DEPARTMENT OF THE AIR FORCE

74TH MEDICAL GROUP
WRIGHT-PATTERSON AIR FORCE BASE OHIO

59

18 April 2001

MEMORANDUM FOR CAPT PERRY CARLSON

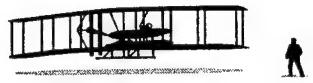
FROM: 74TH MDOS/SGOA
Clinical Investigations Office
4881 Sugar Maple Drive
Wright-Patterson AFB OH 45433-5529

SUBJECT: Clinical Investigation Protocol Amendment

1. The request to amend your protocol, FWP20020016E, "Levels of Hope in Parents of Chronically Ill Children," dated 9 Apr 02, was reviewed and approved via expedited review on 10 Apr 02.
2. If you have any questions, I can be reached at 257-4242.

D Bachman
DEBBIE BACHMAN
Clinical Investigations Coordinator

Appendix C: Cover Letter



WRIGHT STATE UNIVERSITY

Wright State University-Miami Valley
College of Nursing and Health
3640 Colonel Glenn Hwy.
Dayton, OH 45435-0001
(937) 775-3131
FAX (937) 775-4571
www.nursing.wright.edu

Dear Ma'am / Sir

I am a graduate student nurse working on my Master of Science degree in Nursing at Wright State University. I am conducting a research study on the levels of hope in parents of chronically ill children. The Wright-Patterson Pediatric Clinic has agreed to support my study. You are invited to participate in this study by completing the enclosed questionnaires.

The attached quarter is just a small token of my appreciation for your consideration in becoming a participant in my study. The quarter "for your thoughts" is yours to keep whether you choose to complete and return the survey or choose not to complete the survey. Your participation is appreciated and keeping the quarter does not obligate you to further participation.

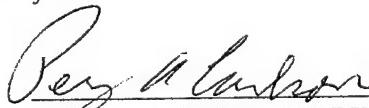
Two surveys are included in the packet. Please have the two caregivers most involved in the child's care separately fill out the surveys and seal them in the blank privacy envelopes provided. Then place both privacy envelopes in the pre-addressed, postage paid envelope and place it in the mail. If you have more than one chronically ill child, please answer the survey questions in regard to the oldest child 18 years of age or younger. It is important that both surveys be completed in regards to the same child.

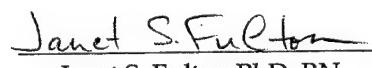
Participation in this study is voluntary. Your decision to participate in this study will in no way affect how you will be treated in future visits to Wright-Patterson Medical Center or the Pediatric Clinic. To assure confidentiality, please do not put your name or any other identifying information on your questionnaires. The number codes on the questionnaires are only to keep the surveys paired and cannot be associated to any particular individual or family. In addition, demographic questions will ask for information such as age, gender, and military status. It should take you just under 15 minutes to complete the forms. Completing these forms may also give you an increased awareness of your own feelings and perceptions of your child's chronic illness.

Only group data results will be reported at the completion of the study. If you would like to receive a summary of the group results after the study is over, please contact me or my faculty advisor after the study is complete (approximately late May).

There are no known risks involved in this study. If you choose to participate in this study, your consent is implied by returning the completed questionnaires by April 30, 2002. Place the completed questionnaires into the privacy envelopes, then the stamped, addressed envelope provided and mail.

If you have any questions about the study or your participation, contact me or my faculty advisor listed below by writing at Wright State University-Miami Valley, College of Nursing and Health, 3640 Colonel Glenn Hwy., Dayton, Ohio 45435-0001 or calling (937) 775-3946. Thank you very much for your assistance in my research study.


Perry A. Carlson, RN, BSN
Graduate Student
Wright State University


Janet S. Fulton PhD, RN
Faculty Advisor
Wright State University

Appendix D: Instruments

Study No. _____

HERTH HOPE INDEX

Listed below are a number of statements. Read each statement and place an [X] in the box that describes how much you agree with that statement right now.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I have a positive outlook toward life.				
2. I have short and/or long range goals.				
3. I feel all alone.				
4. I can see possibilities in the midst of difficulties.				
5. I have faith that gives me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
10. I believe that each day has potential.				
12. I feel my life has value and worth.				

Amount of Assistance Questionnaire – Long Form

Part I - Developmental Skills

ME Msall, MR Tremont & N Lyon
Version 2.0 - October 1, 1998

64

Compared to other children your child's age, how would you describe your child's development in the following areas:

Gross Motor (Walking, running)		Fine Motor (picking up small objects, pencil control, coloring)		Receptive Language
Considerably ahead	5	Considerably ahead	5	Considerably ahead
Slightly ahead of	4	Slightly ahead	4	Slightly ahead
About the same	3	About the same	3	About the same
Slightly behind	2	Slightly behind	2	Slightly behind
Significantly behind	1	Significantly behind	1	Significantly behind
Expressive Language (Talking, signing)		Eating		Dressing
Considerably ahead	5	Considerably ahead	5	Considerably ahead
Slightly ahead	4	Slightly ahead	4	Slightly ahead
About the same	3	About the same	3	About the same
Slightly behind	2	Slightly behind	2	Slightly behind
Significantly behind	1	Significantly behind	1	Significantly behind
Toileting		Hygiene (Washing, brushing teeth)		Grooming (Combing hair, adjusting clothing)
Considerably ahead	5	Considerably ahead	5	Considerably ahead
Slightly ahead	4	Slightly ahead	4	Slightly ahead
About the same	3	About the same	3	About the same
Slightly behind	2	Slightly behind	2	Slightly behind
Significantly behind	1	Significantly behind	1	Significantly behind
Indoor Unsupervised Play		Outdoor Unsupervised Play		Practical Judgment
Considerably ahead	5	Considerably ahead	5	Considerably ahead
Slightly ahead	4	Slightly ahead	4	Slightly ahead
About the same	3	About the same	3	About the same
Slightly behind	2	Slightly behind	2	Slightly behind
Significantly behind	1	Significantly behind	1	Significantly behind
Playing with other Children		Relating to adults (Getting along with parents, teachers)		Coping with Frustration
Considerably ahead	5	Considerably ahead	5	Considerably ahead
Slightly ahead	4	Slightly ahead	4	Slightly ahead
About the same	3	About the same	3	About the same
Slightly behind	2	Slightly behind	2	Slightly behind
Significantly behind	1	Significantly behind	1	Significantly behind

Amount of Assistance Questionnaire – Long Form

Part III – Activities of Daily Living

ME Msall, MR Tremont & N Lyon
Version 2.0 – October 1, 1998

59

Compared to other children your child's age, how much time does your child require to complete the following activities:

		<u>Dressing</u>		<u>Toileting</u> (Using the bathroom)	
Eating		5 Considerably more time than average	4 Slightly more time than average	5 Considerably more time than average	5 Considerably more time than average
		4 Slightly more time than average	3 Average	4 Slightly more time than average	4 Slightly more time than average
Average		3 Slightly less time than average	2 Considerably less time than average	3 Slightly less time than average	3 Considerably less time than average
Slightly less time than average		2 Considerably less time than average	1 Considerably less time than average	2 Considerably less time than average	2 Considerably less time than average
Considerably less time than average				1 Considerably less time than average	1 Considerably less time than average

How much assistance does your child need in completing the following activities

		<u>Dressing</u>		<u>Toileting</u>	
Eating (Using all utensils, consuming food)		5 Total assistance (100%)	5 A lot (75%)	5 Total assistance (100%)	5 Total assistance (100%)
		4 A lot (75%)	4 Some (50%)	4 A lot (75%)	4 A lot (75%)
Total assistance (100%)		3 Some (50%)	3 A little (25%)	3 Some (50%)	3 Some (50%)
A lot (75%)		2 A little (25%)	2 None (0%)	2 A little (25%)	2 A little (25%)
Some (50%)		1 None (0%)		1 None (0%)	1 None (0%)
A little (25%)					
None (0%)					

Does your child use adaptive equipment?

No _____
Yes _____

Please specify:

		<u>Locomotion</u>	
Total assistance (100%)		5 Total assistance (100%)	5 Total assistance (100%)
		4 A lot (75%)	4 A lot (75%)
A lot (75%)		3 Some (50%)	3 Some (50%)
Some (50%)		2 A little (25%)	2 A little (25%)
A little (25%)		1 None (0%)	1 None (0%)
None (0%)			

How much help does your child need to use the adaptive equipment properly?

Total assistance (100%)	5 Total assistance (100%)
A lot (75%)	4 A lot (75%)
Some (50%)	3 Some (50%)
A little (25%)	2 A little (25%)
None (0%)	1 None (0%)

How much time per day does your child require of an adult for supervision and assistance

>12 hours	3 – 4 hours
8 – 11 hours	1 – 2 hours
5 – 7 hours	

Demographic Questionnaire

Directions: Please **DO NOT** put your name on this survey.

Fill in or mark the appropriate **blank**

Parent's Demographic Information

1. What was your age at your last birthday? Age in years: _____
2. What is your gender: Male _____ Female _____
3. What is your military status: Active duty _____; Dependent _____; Civilian _____
4. Are you a parent or legal guardian to the chronically ill child? Yes _____; No _____

If you are not the child's parent, please identify your relationship to the child _____

5. Between you and your spouse (or other), who cares for the chronically ill child at home the majority of the time? Me _____, My spouse _____, Other (please identify relationship to you or your child) _____

Chronically Ill Child's Demographic Information

1. What is your chronically ill child's age in years?: _____ (months if under 1 year: _____)
2. What is your chronically ill child's gender?: Male _____ Female _____
3. Which of the following conditions/illnesses does your child have? Please mark all that apply: Asthma _____; Cerebral Palsy _____; Diabetes _____; Epilepsy (seizure disorder) _____

*Your participation and time is greatly appreciated. If you would like to receive a copy of a summary of this study's results, please request the information by writing or calling the points of contact listed on the cover letter.

Appendix E: Permission to Use Instrument



August 21, 2001

Perry Carlson
3705 E. Hill Lane
Beaver Creek, Ohio 45432

Dear Mr. Carlson,

I appreciate your interest in hope and in the Herth Hope Index. I have enclosed a copy of both the Herth Hope Index and the Herth Hope Scale along with scoring instructions. Both scales are currently being used in research studies by a number of investigators primarily with adults. I have enclosed a reference list I have compiled on hope.

You have my permission to use either the Herth Hope Index or the Herth Hope Scale in your proposed thesis research examining hope. If you decide to use either of my scales in your work I would like to request that you send me an abstract of your completed work and any psychometrics pertaining to my scale. There are no charges connected with using either the scale.

I am excited about your interest in studying hope in parents of chronically ill children and look forward to hearing more about your work. If I can be of any further assistance, please do not hesitate to contact me.

Sincerely,

A handwritten signature in cursive script that appears to read "Kaye Ann Herth".

Kaye Ann Herth, Ph.D., R.N., F.A.A.N.
Dean, College of Allied Health and Nursing

Enclosures

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